ARKANSAS SPINAL CORD COMMISSION

SPINAL COURIER

The spinal cord disability information source for Arkansans since 1989

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Robert Griffin Retires as Russellville Case Manager

Arkansas Spinal Cord Commission (ASCC) Case Manager Robert Griffin announced his retirement effective June 30, 2005. Robert had been employed as a Case Manager in the Russellville office since 1988. Previous to his tenure with ASCC, Robert began his state career in 1973 with Arkansas Rehabilitation Services.

Those individuals he served will miss his dedication and untiring efforts. West Memphis Case Manager Sharon McCoy remembers a statement Robert once made to her, "We are not just here to provide services to our clients but to be dedicated to their well-being as well."

Robert Griffin is presented a plaque honoring his 17 years of service as ASCC Russellville Case Manager by Executive Director Cheryl Vines on June 14, 2005.

"Robert's persistence and tenacity in locating services and resources for the individuals on his case load was worth its weight in gold. He never failed to go the extra mile for anyone who needed assistance," according to Client Services Administrator Patti Rogers.

His fellow Case Managers considered Robert the "Resource Man." If someone needed to locate that hard-to-find piece of equipment, medical information or any other resource, Robert was always the one to call. His years of experience provided invaluable leadership to many new Case Managers.

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Stem Cell Research: An Overview

By Sara Lerman, M.P.H.

In the last few months, stem cell research has been brought into the spotlight by the presidential campaign as well as by the passing of Christopher Reeve, a leading advocate for increased funding of stem cell research. Stem cell research and therapy hold promise for treatment and/or cure of a wide range of diseases and conditions that affect millions of people.

What are stem cells?

Stem cells are known as the "building blocks" of life that give rise to different kinds of tissues or other cells in the body. They are of particular value because they are self renewing in the body, and large quantities of stem cells can be reproduced in the laboratory. Scientists can isolate, manipulate and regenerate these cells to be transplanted in the body's organs to replace or repair damaged or dead cells.

Scientists primarily work with two kinds of stem cells: adult stem and embryonic stem cells. These cells come from both animals and humans.

Adult stem cells renew themselves continuously in some organs of the body. These cells have historically been used with success in the treatment of some diseases. For example, bone marrow stem cells are

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SPINAL COURIER

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ASCC accepts tax-deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

From the Director

We always hear about the regeneration research going on around the world. In April, I had the opportunity to tour the Center for Neuroscience and Regeneration Research (CNRR) at Yale University in New Haven, Connecticut. Paralyzed Veterans of America and United Spinal Association established the center, in conjunction with Yale and the Veterans Administration, in 1988. Not many people were taking 'cure' seriously back then.

Over the past 17 years, the Center for Neuroscience and Regeneration Research has flourished and continued its commitment to the veterans and others with spinal cord disabilities (including multiple sclerosis). Dr. Steve Waxman and his team have an uncanny ability to be able to understand spinal cord injury (SCI), from the molecular structures, axons and neurons, to real life issues like accessibility (the lab is totally wheelchair accessible). The CNRR opened their doors and their labs to our PVA Education Foundation Board for a 'tour.' It was more than that, we had a chance to see the research in action—watching spinal injured rats receiving functional electrical stimulation (FES) on miniature treadmills and looking at spinal cords under the microscope where olfactory ensheathing cells, taken from the nasal mucosa of the rat, is transplanted in the spinal cord and serves to fill the 'gap' and 'reconnect' the spinal cord.

Though a lot of the discussion was above my head, it was amazing to see and hear the work being done in this little building on a VA campus. Certainly here in Arkansas, and in other places, the labs and funding are bigger and better, but the work there at the CNRR was amazing. The staff of scientists, many of whom had come from around the world to work together in the lab, brings a strong commitment to be able to carry out this tedious research and then explain it to us nonscientists.

Then, as always, the presentation ended with a question to Dr. Waxman, "How long before we start working with humans?" He didn't balk, he said the believed in two years the work would be on primates and within five years with humans. I believed him—maybe the cure will come during my lifetime!

Cheryl L. Vines

If you would like to make a contribution, please contact the Commission at **501-296-1788** / **1-800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207

2005 Fall Miniconferences Provide an Update

ASCC will be sponsoring two regional "miniconferences" this fall. The one-day educational sessions will provide an update on issues of importance to people with spinal cord disabilities, their families and care providers.

Topics will include SCI regeneration, the new Medicare Prescription Plan, preserving Medicaid and Medicare services and returning to work, special Medicaid trust funds. In addition, several durable medical equipment dealers will be present with the latest assistive technology and wheelchairs.

The regional miniconferences provide an opportunity for those who cannot come to Little Rock to get an update. So, be sure to mark your calendars!

Thursday, October 6, 2005, **9:00 - 3:00**
Fordyce Room, National Park Medical Center, Hot Springs

Saturday, October 15, 2005, **9:00 - 3:00**
Baxter Regional Medical Center, Mountain Home

Flyers with the registration form will be mailed to those living in the conference regions and the flyers will also be available on the ASCC website. If you would like to get a mailed flyer, please contact us at **1-800-459-1517** or **501-296-1788**.

Spina Bifida Association of Arkansas News

The Spina Bifida Association of Arkansas (SBAAR) has been very busy over the past few months and has many more activities planned for the rest of the year, so mark your calendars:

• **September 24** – Picnic outing to the drag boat races at Lake Catherine. For more informantion, contact Pam Garner at **501-844-7069**.

• **October 15** – Celebrate Spina Bifida Awareness Month at the Second Annual Family Fest at Camp Aldersgate with informative workshops, Halloween activities for the kids and lots of food and fellowship. Contact Vicki Rucker at **501-978-7222**.

• **December 4** – Spina Bifida Christmas Party at Camp Aldersgate. Featuring food, fun, music, gifts for kids and a visit from you know who! Contact Vicki Rucker.

• **Spina Bifida Association Scholarships** – applications are available for $500 scholarships for students with spina bifida who are pursuing post high school education (college, certification, etc.). Contact Vicki Rucker.

• **Spina Bifida Awareness Bracelets** – popular teal rubber, adjustable bracelets (nonlatex) to promote awareness of spina bifida for $1 each. Contact Vicki Rucker.

• The SBAAR also has two new brochures "hot off the press." One describes the medical aspects of spina bifida and the second discusses life with spina bifida—great resources to give to teachers, friends, family and caregivers to help them understand. Copies are available from Vicki Rucker.

SAILS Play Day

The Spa Area Independent Living Services (SAILS) is hosting their 13th Play Day at DeGray State Park on **August 27, 2005**. The day will include adaptive water sports, food, sun and fun!

For additional information, contact SAILS, **501-624-7710**.

Congratulations Justin Bickell!

Justin Duran Bickell, North Little Rock, received a $1,000 scholarship from the Governor's Commission on People with Disabilities at an awards banquet held May 12, 2005. Justin plans to attend the University of Central Arkansas majoring in accounting.

Robert Griffin Retires

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The Commission honored Robert with a dinner June 14th at Tony Roma's Restaurant. His wife Peggy, son Gary and his wife Shannon, daughter Sondra and granddaughter Hallie were present as ASCC staff, former coworkers and friends paid tribute to Robert and wished him well. On behalf of the Arkansas Spinal Cord Commission, Executive Director Cheryl Vines presented Robert a plaque in recognition of his many years of service to the agency and to individuals with spinal cord disabilities.

In preparation for his retirement, Robert and Peggy recently purchased a fifth wheeler and are planning their first road trip. Whatever his future endeavors, we know that he will be successful and we wish him the best!

Protect Your Shoulders

By Tom Kiser, M.D., ASCC Medical Director

Tom Kiser, M.D., ASCC Medical Director

Shoulder pain is common after a spinal cord injury (SCI) as a complication of upper extremity weight bearing and overuse of the upper extremity. The shoulder is designed for mobility and not for stability. After a SCI, the shoulders take on all the workload: from transfers and wheelchair mobility to the routine daily activities of grooming, bathing and dressing.

The shoulders need to be protected and cared for, because the shoulders are the key to independence and good health in an individual with a spinal cord injury. The following are suggestions to help you and your shoulders live happily together:

1. **Avoid a lot of overhead activities**. When your hand is raised above your shoulder, the shoulder muscles are in poor alignment and are unable to provide adequate shoulder stability. Try to do all your routine work in an area below the shoulders and keep overhead reaching to a minimum.

2. Body weight is one factor that can be controlled by diet. By **maintaining a lighter body weight**, less force is placed on the shoulders with transfers and when pushing a wheelchair.

3. **Wheelchair setup is important**. Attempt to get the lightest wheelchair available if using a manual wheelchair, so that the force on the shoulders is decreased with each push. **The more forward the wheels are placed on the frame, the better for the shoulders**. The wheels are easier to reach and push in the more forward position, and it places most of the wheelchair weight distribution over the larger rear wheels, resulting in a decrease in the rolling resistance of the wheelchair. The rear axle should also be positioned at a height where the angle between the upper and lower arm is about 100 to 120 degrees when the hand is top center on the push rim. This position of the axle ensures a good prolonged push with each wheelchair push.

4. **Good wheelchair push mechanics for manual wheelchairs are very important**. A long sustained wheelchair push, with the hand in contact with the push rim from as far back as the individual can reach to the end of the stroke, makes for a very efficient stroke. The recovery phase should also be **long and sustained with the hand below the push rim at all times and with no shoulder hiking**. This relaxed swing of the hand to as far back on the wheel as the individual can reach makes for a relaxed recovery and puts the hand in good position for the next push. This results in minimal shoulder movement and less wear and tear on the shoulders. It also avoids a lot of high impact strokes and pressure on the hands and wrist, since you are pushing the wheelchair with longer, but fewer strokes.

The shoulders are the key to independence and good health in an individual with a spinal cord injury.

5. **The number and quality of your transfers and pressure relief maneuvers are also very important**. Plan your day and your activities to minimize the number of transfers you have to perform. **Transfers to another surface should be as level as possible**; this prevents one shoulder from being higher than the other and therefore in a vulnerable position when transferring. A transfer up into a truck or sports utility vehicle that is way above your chair is hard on your shoulders. **Vary the method and technique of your pressure relief**: mix in a side lean, and a forward lean, as well as a wheelchair pushup. If you have a power wheelchair the use of a power recline system or a tilt system for pressure relief can protect your shoulders.

Finally, **if you are having shoulder pain and need to go to a power wheelchair to protect your shoulders, do it**. You will gain weight with the change from a manual to a power wheelchair (unless you find another exercise outlet—i.e., hand cycle or swimming), but you have only one pair of shoulders, so protect them.

Arm and Shoulder Pain Research

The National Institute on Disability and Rehabilitation Research is funding research in the prevention of arm and shoulder pain in persons with spinal cord injury (SCI). The Northwest Regional SCI System at the University of Washington Department of Rehabilitation Medicine is collaborating with two other SCI centers in this research project. Read about their progress at: **http://depts.washington.edu/rehab/sci/updates/05arm_shoulder_pain.html**

Stem Cell Research

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used to replace the blood cells of patients with leukemia and other cancers.

Although there has been some success with the use of adult stem cells to treat disease, there are some significant limitations. Adult stem cells are present in very small quantities, isolating them is difficult, multiplying them outside the body has not yet been possible in most cases, and they may only be able to develop into a limited number of cell types. The general consensus is that adult stem cells are less versatile and valuable than embryonic stem cells.

Embryonic stem cells are found in embryos 5 or 6 days after fertilization when the embryo becomes a hollow sphere called a "blastocyst." Stem cells are removed from the blastocyst and placed into a culture dish to produce a stem cell "line." Embryonic stem cells have the versatility and potential to become almost any type of cell or tissue and they are easy to isolate and grow in laboratories.

Stem Cell Research

Many scientists are conducting research to uncover the potential benefits of stem cells. Research conducted over the last 20 years on embryonic cells transplanted from animals has provided some important scientific breakthroughs. Research on human embryonic stem cells has only recently become available. Embryonic stem cells seem to provide the best promise for regenerating dead or damaged cells. Specifically, research on embryonic stem cells might lead to cures for cancer, Parkinson's disease, and even spinal cord injury.

Another potential benefit of research involves the nuclear transplantation of stem cells. This technique involves the process of replacing the DNA of an unfertilized egg cell with the DNA from a person's somatic cell, and then triggering the egg to divide to form a blastocyst. The stem cell that would be derived from such a blastocyst would thus contain the patient's own DNA. This technique would genetically match stem cells to a person's DNA, replace or repair damaged tissue, and avoid the often-common result of tissue incompatibility and the body's rejection of transplanted tissues generated from stem cells.

Although there is much to learn from using existing stem cell lines, there are still many obstacles that need to be overcome. For example, there is concern about potential change in the genetic and biological properties of these stem cell lines, as over time, all cell lines in tissue culture change. And when the cells are implanted into an individual, the cells must be made to function with the body's natural cells and avoid rejection. These are just a few of the challenges that lie ahead.

While there are numerous challenges, researchers in the scientific community believe that stem cell therapies will eventually revolutionize medicine. Initially, information from basic research may be

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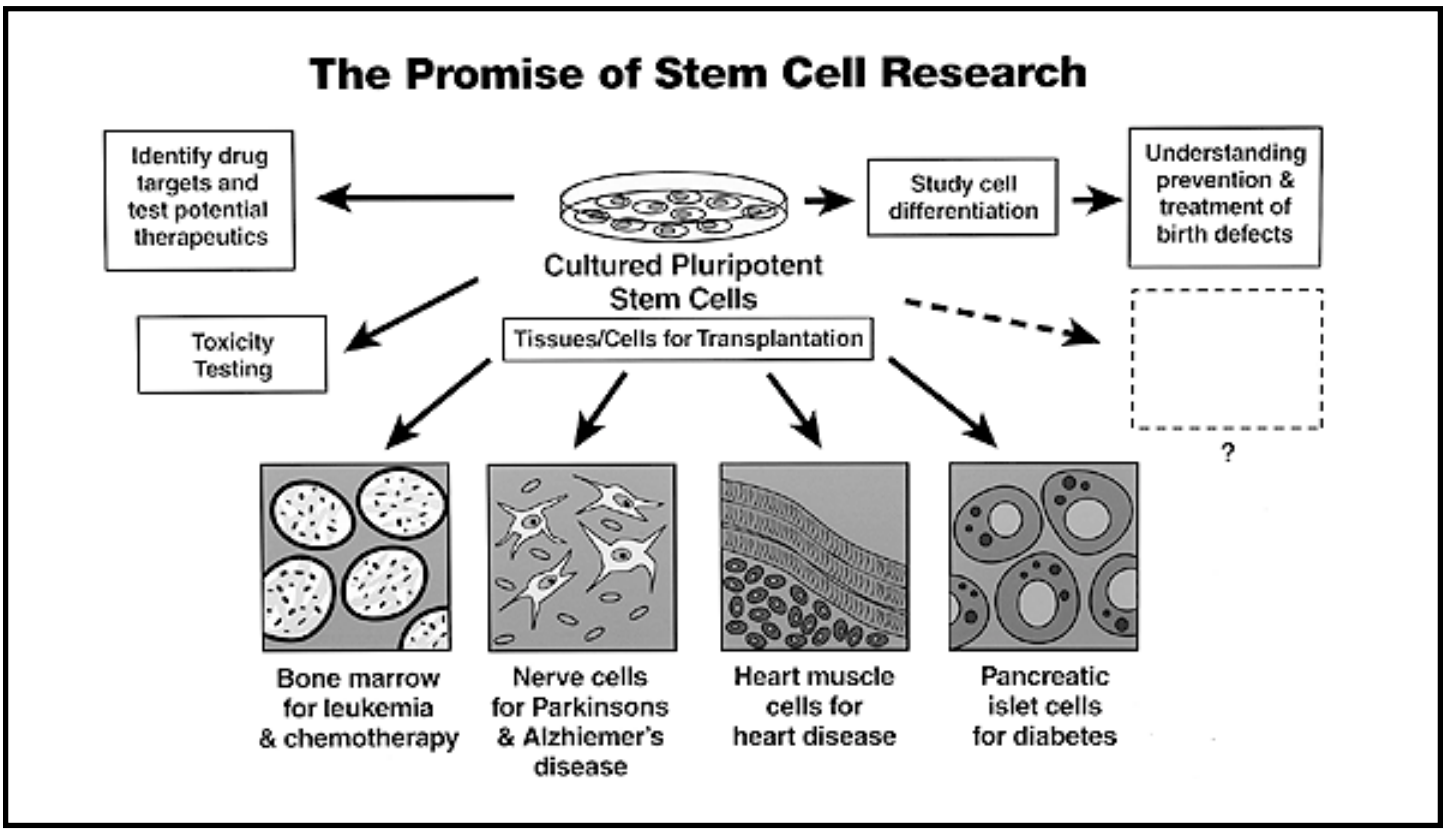

Up Close and Personal: Bernie Quell

This is the seventh in a series of articles profiling the ASCC Case Managers.

Bernie Quell began his career with the Commission in March of 2000. Initially, he worked as a Case Manager for the Little Rock and Benton areas. He later assumed the role of Intake Coordinator and continues to serve in that capacity today.

Before coming to work for ASCC he worked as a Vocational Specialist with the brain injured population and the chronically mentally ill. He also served as Director of Education for a hospice program. Recently, Bernie taught a graduate level rehabilitation class through the University of Arkansas at Little Rock one evening a week.

Bernie has been instrumental in developing the spinal cord disability (SCD) support group that meets the third Thursday of each month in Sherwood. Bernie feels not only clients benefit from the meetings, "My job as Intake Coordinator places me in the presence of individuals and families whose lives are changed forever. I find the SCD support group necessary for my well-being. The support group keeps me grounded in the fact that there is quality of life after spinal cord injury. I learn so much from the people I serve and I am amazed at the resiliency of the human spirit. The variety of my work experience calls me to be a witness to individual tragedy and triumph. I welcome each day and recognize how a 'normal' day is such a blessing and a cause for celebration."

PROFILE:

Date And Place Of Birth: February 11, 1951, in Monroe, MI.

Family Member: Katherine E. Snyder, wife.

One Thing People Would Find Surprising About Me Is: I am accomplished drummer and played in a country band on weekends for over six years.

I Have A Need To Be: Busy and productive.

If I Did Not Live In Little Rock, I Would Want To Be: In Ouray, CO.

My Favorite Movie Is: *Time Bandits.*

My Favorite Song Is: *Don't Bring Me Down* by the Animals.

The Guest At My Fantasy Dinner Party Would Be: Clayton Moore (a.k.a., The Lone Ranger).

I Am Most Comfortable With People Who Have: An understanding of how everyone is unique.

My Favorite Pastime Is: Being outdoors.

My Pet Peeve Is: People who blame others and will not claim any individual responsibility.

The Best Advice I Ever Received Was: If you can't get along with yourself, you will never be able to get along with anyone else.

My Favorite Saying Is: "Be Here Now!" (Ram Dass).

I Knew I Was Grown Up When: At the age of 13, I saved an elderly main from drowning and was awarded the Boy Scout Certificate for Heroism Award.

The One Thing I Always Wanted To Do But Have Never Done Is: Be a lead singer in a band.

My Hobbies Include: Pottery, woodworking, gardening and running.

One Word To Sum Me Up: Optimistic.

Welcome Cathy!

Cathleen Bailey joined the staff of the Arkansas Spinal Cord Commission (ASCC) on May 2, 2005, as our Fiscal/Personnel Officer. Cathy replaces Diana Hoke, who had served in that position for 16 years and left to return to her family home in northwest Arkansas.

Cathy brings a wealth of education and experience to her new position. She holds a bachelors degree in accounting from University of Arkansas at Little Rock and has worked in many different areas of accounting both in the public and private sector. She came to the Commission from Arkansas Department of Health where she was an accounting supervisor. Her role at the Commission is multifaceted, as she oversees all of the expenditures made, as well as coordinating the hiring and training of staff, and manages our inventory of equipment. Cathy's strong work ethic and calm demeanor are already proving great assets for ASCC.

A newlywed (she was on her honeymoon when we called her for an interview), Cathy and her husband Tim live with her children, Meagan, 16 and Alex, 14 and dog, Sadie in Little Rock. When she is not at work or playing chauffeur to teens, she loves to make jewelry. Please join us in welcoming Cathy to our Commission!

Cathy Bailey became the new ASCC Fiscal/Personnel Officer in May 2005.

Stem Cell Research

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used to further explore the causes of diseases which result from cell damage or degeneration and from cell death. Stem cell therapies may then attempt to replace cell loss and induce repair mechanisms by having the healthy cells become integrated into a patient's body and begin to function like the patient's own cells.

The Controversy
Human embryonic stem cell research has spurred a great deal of controversy. One debate is about the ethical and legal issues of when life begins and the rights of an embryo. Controversy is also specifically related to the source of embryonic cells. Some will only accept, or oppose, the use of stem cells derived from embryos created specifically for research from eggs and sperm donated by volunteers who have no reproductive intent. Others may only accept, or oppose, the use of cells derived from embryos produced in fertility clinics that are no longer needed for reproductive purposes.

Funding
In August 2001, President Bush announced that he would approve federal financial support for research that uses embryonic stem cells already being cultured in laboratories. However, no federal funding will be made available for the development of new lines that involve the creation or destruction of additional embryos. Currently, there are about 60 stem cell lines resulting from excess human embryos identified by the National Institutes of Health (NIH) as produced before the August 2001 announcement.

Although the NIH is considered a vital funding source, there are few state laws and no federal law that prohibit funding from private sources. This means private funds can be used for the development and use of human embryonic stem cells derived from excess embryos created by in vitro fertilization for the purposes of research or by nuclear transplantation.

Supporters of human embryonic stem cell research believe federal funding would speed the progress of health benefits faster than private funding. Funding from the private sector is often tied to commercial applications, such as new drugs. Therefore, many companies in the private sector may not be inclined to fund basic stem cell research.

Conclusion
Although stem cell research is controversial, it explores the fundamental and basic mechanisms of the cell and how tissues develop, specialize, and differentiate. Most scientists are optimistic that stem cell therapies hold a great deal of promise for treating and curing numerous conditions and diseases that affect millions of individuals. However, it will take time, continued research and funding to translate research information into medically useful therapies.

*Sara Lerman, MPH, is a Program Manager for the American Association of Spinal Cord Injury Nurses (***www.aascin.org***).*

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The Squeaky Wheel

The squeaky wheel . . . gets the grease! This column is all about grease—things that make life for persons with a spinal cord disability go smoother and ease your way in the world. “Things” can be hints, equipment adaptations, innovations, tricks-of-the-trade, procedural shortcuts, life experiences or things you “should have done but didn’t.”

Kristi passes on a “slick” idea in the use of transfer boards.

Here’s some ‘grease’ for you—literally! We all know how hard it is to get across our transfer boards when we don’t have any clothes on. This was such a struggle for me until my dad came up with this brilliantly SIMPLE idea . . . baby oil! Yep! That’s all it takes. Just a good little coat of Johnson’s will glide you right to the other side in one smooth move. And it’s good for your skin, too!

You may be thinking I’m crazy. When my dad mentioned it to me, I thought he’d lost his ever lovin’ mind!

I was too chicken to try, thinking I’d slide right off onto the floor. But after struggle, after struggle, after struggle, I got desperate and decided to be brave. Well, I’ll have you know that no matter how much oil I put on my board, I never once have felt out of control, and it’s been nothing but SMOOOOOOOOOTH sailin’ every since!

I’m Kristi and I received my T6 complete spinal cord injury about eight-and-a-half years ago. Hope my little spot of grease helps YOUR squeaky wheel!

We invite you to send in your helpful hint–your bit of “grease.” Contact your ASCC Case Manager, write us or e-mail us at **courier@arspinalcord.org**.

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